Full title:
What is standard care for people with learning disabilities and behaviour that challenges and what does it cost?

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Accessible summary

- The provision of care and support for people with learning disabilities and behaviour that challenges in England is mixed.
- Children and young people with learning disabilities and behaviour that challenges are likely to live within the community, while adults will be in residential care.
- Overall, supporting people with learning disabilities and behaviour that challenges within the community is likely to be less expensive than supporting them in residential care.

Summary

We describe current care arrangements in England for children, young people and adults with learning disabilities and behaviour that challenges, and estimate their comparative costs. A two-round Delphi exercise was performed in March and April 2014, followed by a costing exercise. The study finds a mixed picture: participants reported that 60%-87% of children, 66%-88% of young people and 34%-47% of adults were likely to be living within the community. Annual cost of care would range between £39,612 and £74,876 for children, between £35,235 and £52,832 for young people, and between £81,478 and £94,799 for adults. While residential-based care may continue to be necessary for respite or for individuals with particular needs, community-based care may be an economically attractive alternative, supporting the inclusion of people with learning disabilities and behaviour that challenges within their communities, potentially at a lower cost.

Introduction

In England, 1.14 million people have learning disabilities, of whom 236,000 are children and 908,000 are adults (Emerson *et al.* 2013a). Behaviours that challenge, such as aggression and self-injury, are presented in 10-15% of people with learning disabilities, with prevalence peaking for those aged 20-49 years (Emerson *et al.* 2013b).

'Challenging behaviour' has been defined as behaviour 'of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion' (Royal College of Psychiatrists *et al.* 2007, p. 14). The care offered to children and adults with learning disabilities and behaviour that challenges in England includes a range of interventions, from community-based support to residential schools and care placements (Department of Health [DH] 2007). Since the Winterbourne View report, there has been policy commitment to shift the focus of care from residential-based to community-based models (DH 2012a,b; DH 2013). In particular, person-centred approaches and positive behaviour support have been recommended to support people with learning disabilities living within the community (DH 2014; Local Government Association & National Health Service England [LGA & NHS England] 2014). This change may have important cost implications. On the one hand, costs may increase due to the need for additional staff training and supervision (Mansell & Beadle Brown 2004); on the other hand, there is an opportunity to reduce expenditure on high-cost residential settings.

Previous studies have suggested that the annual costs of residential placements for people with severe learning disabilities might exceed £178,000 for children (McGill 2008) and £185,000 for adults (McGill & Poynter 2012) (at 2012/13 prices).

Despite the attention focused on this area, there is limited evidence on patterns of utilisation of the different forms of community-based services currently available across the country. Understanding the actual provision of services is paramount, not only for policy-makers and commissioners making decisions about resource allocation, but also for care professionals making decisions about use of services, and services users and their carers using them. This study aims to describe the care arrangements currently received by children, young people and adults in England; and then to build on those results to estimate their comparative costs.

Method

We carried out a two-round Delphi exercise (Hsu & Sandford 2007) in March and April 2014. This was followed by a costing exercise. We describe both below.

Delphi exercise

A Delphi exercise is a consensus process relying on a group of experts. This method was chosen due to the lack of direct evidence in the literature on the topic. The Delphi exercise in this study comprised a face-to-face focus group and two rounds of questionnaires, one completed immediately after the focus group and the second by email.

The Delphi questionnaire was designed by two of the authors (VI, MK). It included six vignettes of people with learning disabilities and behaviour that challenges: four for children and two for adults. The vignettes were provided by three other authors (FJB, CR, MS) from their clinical practice but with names and small details changed to preserve anonymity. The detailed vignettes are in the Appendix. For each vignette on children, two questions were asked:

- What would be likely to happen to this (young) person in terms of care placement/setting in your locality?
- What would be likely to happen to this young person in terms of care placement/setting in your locality when she/he reaches age 18?

For each vignette on adults, only the first question was asked. The first question for children aimed to capture service provision in childhood; the second question concerned provision for children transitioning to adult services that we will refer to as young people. The number of vignettes was hopefully sufficient to capture much of the diversity in needs of people with learning disabilities and behaviour that challenges, yet small enough to allow completion in a reasonable amount of time (c.20 minutes). Two questions were asked for adults, and four for children, because each of the latter included a question for children and one for young people.

First round

The first round of the Delphi exercise took place during a meeting of the Challenging Behaviour National Strategy Group in March 2014 in London. Participants had experience in caring for or working with people with learning disabilities and

behaviour that challenges. Groups of three or four people worked together, using a paper copy of the questionnaire with open-ended questions. They were asked to discuss the vignettes in their group and then complete the questionnaire individually. At the end of the meeting, relevant organisations (see below) were approached to help with the second round. The study was presented and consent was obtained verbally during the meeting.

Results of the first round were extracted and analysed in MS Excel 2010. Participants' characteristics were described and response rates calculated. For each question, answers given by participants were listed, common answers grouped, discussed within a subgroup of authors, and then adapted for the second round. Analyses were performed in Excel 2010.

Second round

The second round of the Delphi exercise was conducted using an online tool (SurveyMonkey). Participants were contacted by email and invited to complete the online questionnaire. Invitations were sent using mailing lists from organisations approached during the first round (British Institute of Learning Disabilities, Challenging Behaviour Foundation, Council for Disabled Children, Skills for Care, Tizard Centre). Participants were provided with the six vignettes and multiple choice questions listing the possible packages of care identified during the first round. They were asked to select the first and the second most likely scenarios in their locality for each child and adult described in the vignettes. The total number of questions was therefore ten: eight for the vignettes on children, and two for adults. Participants could answer as many questions as appropriate based on their experience, thus some of them may have answered fewer than ten questions. Information on the study and the use of data after completion was described in the invitation email. Participant characteristics were described. For each question, we calculated the number and percentage of responses, the number and percentage of participants who chose each scenario of care and the group average (level of agreement). Results were presented by age group: children, young people, and adults. Results for children and young people correspond to the answers to the first and second question respectively for the four vignettes on children. Results for adults correspond to the question for the two vignettes on adults. Analyses were performed in STATA 13.

Costs

Following the second round, each scenario of care for children and adults was costed. Cost figures were either taken from previous research (Curtis 2013; Clifford & Thobald 2012; Iemmi *et al.* 2015; Iemmi *et al.* 2016a,b) or from additional analysis performed on two datasets made available to us (Beresford *et al.* 2012; Tyrer *et al.* 2009). Costs included were education, health and social care (inpatient, outpatient, community-based services, and residential respite care). Costs incurred by families and carers were not included due to lack of data. Costs were reported as weekly and annual figures, as individuals may require support with different packages of care in different periods as their needs and personal contexts change. Costs were set at

2012-13 price levels, inflated if needed using the Hospital and Community Health Services Pay and Prices Index (Curtis 2013; details in Annexes 1 and 2).

After the second round, for each vignette, we combined weekly and annual costs with the probability of occurrence of each scenario (from the Delphi) to get a weighted average cost for each vignette. Results are presented by age group: children, young people, and adults. Analyses were performed in SPSS 21, STATA 13, and MS Excel 2010.

Ethical approval
Ethical approval for the overarching study was obtained from the Social Care Research Ethics Committee (12/IEC08/0026).

Results

Delphi questionnaire (first round)

Participants
Thirty people took part in the first round, 20 women and 10 men. Their average length of experience in relevant health and social care areas was 22.4 years (SD=9.9, range 5-41). There were seven care professionals (23%), five policy-makers (17%), four carers (13%), two providers (7%), two individuals working in the third sector (7%), one commissioner (3%), one individual working in university-based research (3%), and eight individuals with more than one of these affiliations (27%). All were working in the United Kingdom.

Types of care and support Mean number of questions answered per participant was seven out of ten (range 3-10). Mean number of answers per question provided by the 30 respondents was 21 (range 18-23). Nine possible answers were identified from the open-ended questions. Four were residential-based: secure unit; psychiatric hospital; 52-week residential (school) placement; 38-week residential (school) placement. The other five answers were community-based scenarios: living in supported accommodation; living at home with community-based social and mental health care (child and adolescent mental health services, adult mental health services, community learning disability teams) and positive behaviour support; living at home with community-based social and mental health care; living at home with community-based social care; and living at home without any support. Living in supported accommodation was only available for young people and adults.

Delphi questionnaire (second round)

Participants
One hundred and nineteen participants took part in the second round. One individual working outside the UK was excluded from the analysis because differences in service provision between countries would potentially bias the results. Out of 118 eligible participants, 73 provided their socio-demographic characteristics (Table 1).

<TABLE 1>

Types of care and support Mean number of questions answered by each participant was six out of ten (range 0-10). Mean number of answers per question provided by the 118 respondents was 58 (range 45-65). Overall, we found broad variability in services used, both between and within vignettes.

Table 2 summarises participants' answers on packages of care for children in the four vignettes. When considering the first choice only, 66% of participants reported that the child described in vignette 1 was likely to be living in the community, either at home with community-based social and mental health care (34% of all responses) or without any support (6%). For vignette 2, 87% of participants reported the child was likely to be living in the community, either at home with community-based social and mental health care (32%) or without any support (25%). For vignette 3, 76% of participants said that the child was likely to be living in the community, either receiving community-based social and mental health care (37%) or (but rarely) without any support (8%). For vignette 4, 60% of participants said that the child was likely to be living in the community, receiving community-based social and mental health care (29%) or (but less likely) without any support (6%).

<TABLE 2>

Table 3 summarises participants' answers on packages of care for children in the four vignettes when *transitioning to adult services*. When considering the first choice only, for vignette 1, 79% of participants indicated that the child was likely to be living in the community when transitioning to adult services, either at home with community-based social and mental health care (27% of all responses) or sometimes without support (16%). For vignette 2, 88% of participants said that the child was likely to be living in the community when transitioning to adult services, without any support (31%) or at home with community-based social and mental health care (26%). For vignette 3, 80% of participants reported that the child was likely to be living in the community when transitioning to adult services, either at home with community-based social and mental health care (24%) or without support (15%). For vignette 4, 66% of participants said that the child was likely to be living in the community when transitioning to adult services, at home with community-based social and mental health care (18%) or sometimes without support (10%). However, the most commonly suggested scenario for vignette 4 was a 52-week residential placement (19%).

<TABLE 3>

Table 4 summarises participants' answers on packages of care for adults in the two vignettes. When considering the first choice only, for vignette 5, 53% of participants said that the adult was most likely to be living and receiving residential-based care, mainly 52-week residential placement (34% of all responses). For vignette 6, 66% of participants said that the adult was likely to be living in and receiving residential-based care, either 52-week residential placement (25%), psychiatric hospital (23%), or secure unit (18%). Few participants considered adults in vignettes 5 or 6 would be living in the community without any support (4% and 2%, respectively).

<TABLE 4>

Costs of care and support
Tables 5 and 6 summarise the weekly and annual package costs of the scenarios for children and adults respectively. Costs of scenarios for adults were also used for young people. Costs are generally higher for residential-based compared to community-based care, for both children and adults. The high cost associated with positive behaviour support was due to the fact that all three positive behaviour support interventions for which costs were available were relatively short-term (22 months for children; 12 months for adults) but intensive (National Institute for Health and Care Excellence [NICE] 2015, pp. 224-227).

<TABLE 5>

<TABLE 6>

Costs of care and support for the vignettes Table 7 presents the weighted average weekly and annual care package costs for each vignette. Overall, we found broad variation in reported services across vignettes. When considering the first choice only, annual (weighted) cost of care ranged between £39,612 (vignette 2) and £74,876 (vignette 4) for children, between £35,235 (vignette 2) and £52,832 (vignette 4) for young people, and between £81,478 (vignette 5) and £94,799 (vignette 6) for adults.

<TABLE 7>

Discussion

Our study adds to the very limited evidence, not only on packages of care currently available to people with learning disabilities and behaviours that challenge across England, but also on the costs of supporting individuals in these various settings. Our study presents a mixed picture of care and support received by people with learning disabilities and behaviour that challenges. Our results show that while community-based care was most likely for children and young people, there was a shift toward residential and inpatient care in adult life, with higher associated costs.

On the one hand, the increase in the use of residential-based care in adulthood may perhaps be explained by increasing risk of comorbidities later in life and difficulties faced by ageing family carers in supporting adults with learning disabilities (Ryan *et al.* 2013). On the other hand, attempts to support people in the community may have been hindered by the lack of a recovery-based service model, that could have supported them in developing 'greater ability to manage their own lives, stronger social relationships, a greater sense of purpose, the skills they need for living and working, improved chances in education, better employment rates and a suitable and stable place to live' (DH 2011, p. 6). We found that residential-based care is more costly than community-based care, and greater reliance on residential options later in life pushes up costs in adulthood. When considering the cost of supporting

individuals, costs are generally intermediate between those for full-time support through community-based care and full-time support through residential based care. Our results provide a preliminary economic case for supporting people within the community, as already encouraged in recent policy announcements (DH 2012a,b; DH 2013). Few previous studies have looked at this area, but Barron *et al.* (2013) estimated residential-based care at 65% of the total cost of caring for adolescents with learning disabilities and behaviour that challenges, while Knapp *et al.* (2005) estimated this cost at 85% for adults.

The high variability in costs across the vignettes reflects high variability in people's needs and circumstances. Knapp *et al.* (2005) found that support costs increase with the severity of learning disabilities and behaviour that challenges. The heterogeneity of the answers for the same vignette in our study also reflects variability in service provision across the country, with residential-based care still being the only available service in some localities.

The 'real' individuals behind the six vignettes were all supported in the community, living at home and receiving community-based social and mental health care with positive behaviour support. Among packages of care received in the community, living at home and receiving community-based social and mental health care with positive behaviour support was estimated to be the most expensive. However, the positive behaviour support services used to build our vignettes and costs were relatively short-term intensive interventions, and preliminary results (Iemmi *et al.* 2015; Iemmi *et al.* 2016a,b) have shown them to maintain people with learning disabilities and behaviour that challenges in the community with less intensive and less costly support in the long term.

Strengths and limitations

In the absence of primary data, the Delphi exercise allowed us to draw on a wide range of experts' views about the availability of care for people with learning disability and behaviour that challenges in England, and then to estimate the associated costs. The study benefitted from collaboration between family (unpaid) carers, care professionals and researchers.

However, the study has limitations. First, the variability of both service provision across the country and individual needs and circumstances made it difficult to establish a comprehensive list of scenarios. Comments received after completion of the Delphi exercise identified three additional scenarios: 52-week residential (school) placement with positive behaviour support, 38-week residential (school) placement with positive behaviour support, and living at home with community-based social care and positive behaviour support. Second, differences in participants' experience in relation to service provision for people with learning disabilities and behaviour that challenges might mean that some responses may not be as well-informed as others. We were not able to make adjustment for this possibility. Third, the lack of information on unpaid care limited our cost estimation to formal care only, even though it is well-known that support received from families and carers represents a 'large and hidden portion of the overall cost of caring' (Romeo *et al.* 2009, p. 436) estimated to 86% of the overall cost of support of adults with learning disabilities in England (Romeo *et al.* 2009). Slightly lower estimates were found in Australia, where

support received from families and carers accounted for 77% of the overall cost of support of children with learning disabilities (Doran *et al.* 2012). Fourth, during the estimation of the package costs, the limited availability of economic evidence on services provided to people with learning disabilities and behaviour that challenges made it necessary to use multiple sources of data, sometimes based on small samples (Annexes 1 and 2). In particular, cost data for positive behaviour support were only available for three short-term intensive interventions, whereas positive behaviour support - as a personalised approach - may be provided longer-term for people with more complex needs (McClean *et al.* 2005). Finally, in the absence of evidence, package cost estimates were reported as weekly and annual figures, based on the assumption that different packages of care may be required by individuals in different periods as their needs and personal contexts change.

Implications

Since the Winterbourne View report, there has been policy commitment to provide services to people with learning disabilities and behaviour that challenges in the community, while maintaining residential-based care for respite purposes or for people with the most complex needs (DH 2012a,b; DH 2013). Person-centred approaches and positive behaviour support have emerged as ways to support people with learning disabilities in the community (DH 2014; LGA & NHS England 2014). NICE has published clinical guidance on learning disability and behaviours that challenge that is intended to help develop local practice around evidence-based interventions (NICE 2015). However, translation of the first policy commitment and the emerging evidence into practice varies across the country. Moreover, implementation problems have been highlighted, in particular the need for a change in the social and organisational context (Allen *et al.* 2013). Broader changes in culture would need to be achieved at all levels, through increases in both capability and capacity. The former might include training of different stakeholders – such as families, schools, health and social care providers – to try to prevent behaviours that challenge, to support early diagnosis and intervention, and to maintain quality of life for people with learning disabilities and behaviours that challenge. The latter (increased capacity) might be achieved through scaling-up interventions, including training staff to introduce new ways of working and perhaps aiming for new skill combinations.

This study provides a description of care arrangements currently received by children, young people and adults with learning disabilities and behaviour that challenges in England, and their comparative costs. It provides preliminary economic evidence for supporting people with learning disabilities and behaviours that challenge within the community. This information may be useful to policy-makers and commissioners to inform decisions on resource allocation, care professionals to inform decisions on best available services, and indeed to people with learning disabilities and behaviour that challenges and their carers to help their understanding of care and support that might be available to them. However, more robust evidence is needed to support key decisions by any of these groups, and future studies may benefit from the availability of new data: the Department of Health is committed to develop a new learning disability minimum data set (DH 2012a; DH 2013) and Clinical Commissioning Groups are required to keep local

registers of all people with behaviour that challenges (DH 2013; Health & Social Care Information Centre 2013).

Conclusion

While community-based care is reported to be the most likely support received by children and young people with learning disabilities and behaviour that challenges, residential-based care is still the most likely support for adults. This difference means that public sector costs will be higher in adulthood.

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Appendix: Vignettes

Vignette 1: Matthew

Matthew is an 11 year old mixed-race British boy who lives alone with his mother and has no contact with his father. Matthew has a diagnosis of autism, attention deficit hyperactivity disorder (ADHD) and severe learning disability. Matthew's mother has some medical and mental health difficulties, and is socially isolated with little support from family or friends. Matthew displays behaviours which challenge across all settings, include physical aggression towards others (e.g. hitting, kicking, scratching, pulling hair), destructive behaviours (e.g. pulling furniture over, snapping dvd's), PICA (i.e. eating liquid soap), refusing to wear shoes outside and to receive sufficient personal care from his mother, scratching himself when stressed and urinating in inappropriate places and faecal smearing.

Vignette 2: Abshir

Abshir is a 15 year old Black Somali Muslim boy who lives with his parents and 7 siblings. Abshir has a diagnosis of severe intellectual disability and epilepsy, and he is at significant risk of exclusion from school and other services. The main concerns included physical aggression towards teaching staff, resulting in two teachers requiring medical attention. Abshir also presents with self-injurious behaviour such as banging his head on the floor and walls and teachers feel unable to manage this effectively and safely. Further to this, Abshir presents with non-compliance both at home and at school, and if he doesn't get his own way, he would break or throw objects. Abshir's parents do not want him to be looked after by anyone else and often deny needing any additional support at home. There is a history of care packages breaking down. The parents report low-level behavioural challenges at home and reported to social care that they were managing ok.

Vignette 3: Raj

Raj is a 12 year old boy, with a severe learning disability diagnosis. He experienced a major brain injury while an infant following an operation to remove a tumour. Raj is very active and likes to engage with people around him. He communicates with two gestural signs (i.e. hand to mouth to indicate food and pointing to himself) and indistinct vocalisations. His play is non-symbolic and sensory-related. He does not participate in individual or group classroom activities without high staff support. Even with high levels of staff support in school his behaviour is difficult to manage and is highly disruptive, often starting with tipping tables and chairs over, pulling things off walls and running around the room, escalating into aggression towards people. Another problematic behaviour is smearing faeces. His parents do not take him out of the house because they cannot manage his behaviour in public settings.

Vignette 4: Ben
Ben is a 13 year old boy, with an autism spectrum disorder and severe learning disability diagnosis. He communicates with PECS cards alongside a small number of Makaton signs and spoken words. He has limited attention skills and moves quickly from one interest to another. He is a physically big child and has a long history of engaging in aggressive behaviour (i.e. hitting, kicking, biting), usually when he doesn't want to do something or wants to get access to something (e.g. food). Ben wears a pad at all times and has never demonstrated any continence skills. He engages in sexualised behaviour (i.e. masturbating and grabbing) towards female staff, usually when being changed when he is soiled. Previous attempts to teach Ben to use the toilet have been unsuccessful. Staff are increasingly feeling uncomfortable and anxious about changing him in the small bathroom. Ben's parents report that the aggressive and sexualised behaviours are also happening at home and they are struggling to manage.

Vignette 5: Anna
Anna is a 52 year old woman with a severe intellectual disability diagnosis. Anna has lived in a variety of placements including assessment and treatment units, residential settings and a community tenancy that broke down, meaning she moved again to a residential setting (out of borough). Anna shows high levels of behaviour that challenges (aggression, spontaneous urination, undressing, screaming) and limited opportunities to engage in any meaningful activity or access the community.

Vignette 6: Marc
Marc is a 27 year old man with a severe intellectual disability, cerebral palsy, epilepsy and PICA. Although Marc lived in the community he had several admissions to an Assessment and Treatment Unit (ATU). Following his most recent discharge from an ATU, there has been a significant increase (frequency and intensity) in behaviours that challenge. These include eye poking, smearing faeces, tearing clothing, hitting, biting, tearing and eating furniture, self-induced vomiting, loud vocalisations/screaming, banging walls and furniture and eating his incontinence pads.

Table 1 Characteristics of participants in the second round (N=118)

	Number (%)
Gender	
Female	53 (73%)
Male	20 (27%)
Role	
Care professional	38 (52%)
Provider	9 (13%)
Third sector	6 (8%)
Commissioner	3 (4%)
Carer	3 (4%)
University/research centre	3 (4%)
Policy maker	1 (1%)
Other roles	5 (7%)
More than one role	5 (7%)
Country	
England	65 (89%)
Wales	4 (5%)
Scotland	2 (3%)
Northern Ireland	2 (3%)
Years of experience (mean, SD)	17.9 (9.7)

Table 2 Participants' choice of scenario of care for children with learning disabilities and behaviour that challenges

	First choice (N, %)				*Second choice (N, %)*			
	Vignette 1	**Vignette 2**	**Vignette 3**	**Vignette 4**	**Vignette 1**	**Vignette 2**	**Vignette 3**	**Vignette 4**
Secure unit	1 (2%)	0 (0%)	0 (0%)	0 (0%)	1 (2%)	1 (2%)	0 (0%)	3 (5%)
Psychiatric hospital	0 (0%)	1 (2%)	0 (0%)	1 (2%)	1 (2%)	3 (5%)	1 (2%)	4 (7%)
52-week residential school placement	12 (18%)	4 (6%)	6 (10%)	12 (20%)	12 (19%)	8 (13%)	6 (11%)	10 (17%)
38-week residential school placement	9 (14%)	3 (5%)	8 (14%)	11 (18%)	17 (27%)	6 (10%)	10 (18%)	13 (22%)
Sub-total: residential-based settings	**22 (34%)**	**8 (13%)**	**14 (24%)**	**24 (40%)**	**31 (50%)**	**18 (30%)**	**17 (31%)**	**30 (51%)**
Living at home with community-based social and mental health care and positive behaviour support	7 (11%)	11 (17%)	10 (17%)	9 (15%)	4 (6%)	3 (5%)	4 (7%)	7 (12%)
Living at home with community-based social and mental health care (CAMHS/CLDT)	22 (34%)	20 (32%)	22 (37%)	18 (29%)	10 (16%)	11 (19%)	14 (26%)	7 (12%)
Living at home with community-based social care	10 (15%)	8 (13%)	8 (14%)	6 (10%)	9 (15%)	16 (27%)	16 (29%)	10 (17%)
Living at home without any support	4 (6%)	16 (25%)	5 (8%)	4 (6%)	8 (13%)	11 (19%)	4 (7%)	5 (8%)
Sub-total: community-based settings	**43 (66%)**	**55 (87%)**	**45 (76%)**	**37 (60%)**	**31 (50%)**	**41 (70%)**	**38 (69%)**	**29 (49%)**
Total	**65(100%)**	**63(100%)**	**59(100%)**	**61(100%)**	**62(100%)**	**59(100%)**	**55(100%)**	**59(100%)**

Note: CAMHS = Child and Adolescent Mental Health Service. CLDT = Community Learning Disability Team.

Table 3 Participants' choice of scenario of care for young people with learning disabilities and behaviour that challenges transitioning to adult services

	First choice (N, %)				*Second choice (N, %)*			
	Vignette 1	**Vignette 2**	**Vignette 3**	**Vignette 4**	**Vignette 1**	**Vignette 2**	**Vignette 3**	**Vignette 4**
Secure unit	1 (2%)	0 (0%)	1 (2%)	0 (0%)	4 (7%)	2 (4%)	2 (4%)	6 (10%)
Psychiatric hospital	0 (0%)	0 (0%)	0 (0%)	3 (5%)	1 (2%)	4 (7%)	1 (2%)	2 (3%)
52-week residential placement	10 (16%)	7 (12%)	11 (18%)	12 (19%)	9 (15%)	6 (11%)	5 (9%)	8 (14%)
38-week residential placement	2 (3%)	0 (0%)	0 (0%)	6 (10%)	3 (5%)	2 (4%)	6 (11%)	5 (9%)
Sub-total: residential-based settings	**13 (21%)**	**7 (12%)**	**12 (20%)**	**21 (34%)**	**17 (29%)**	**14 (26%)**	**14 (26%)**	**21 (36%)**
Living in supported accommodation	9 (15%)	5 (8%)	6 (10%)	6 (10%)	12 (21%)	8 (14%)	10 (18%)	9 (16%)
Living at home with community-based social and mental health care and positive behaviour support	6 (10%)	9 (15%)	10 (16%)	9 (15%)	6 (10%)	7 (12%)	7 (12%)	5 (9%)
Living at home with community-based social and mental health care (AMHS/CLDT)	17 (27%)	16 (26%)	15 (24%)	11 (18%)	10 (17%)	12 (21%)	16 (28%)	13 (22%)
Living at home with community-based social care	7 (11%)	5 (8%)	9 (15%)	8 (13%)	12 (21%)	10 (18%)	7 (12%)	7 (12%)
Living at home without any support	10 (16%)	19 (31%)	9 (15%)	6 (10%)	1 (2%)	5 (9%)	2 (4%)	3 (5%)
Sub-total: community-based settings	**49 (79%)**	**54 (88%)**	**49 (80%)**	**40 (66%)**	**41 (71%)**	**42 (74%)**	**42 (74%)**	**37 (64%)**
Total	62(100%)	61(100%)	61(100%)	61(100%)	58(100%)	56(100%)	56(100%)	58(100%)

Note: AMHS = Adult Mental Health Service. CLDT = Community Learning Disability Team.

Table 4 Participants' choice of scenario of care for adults with learning disabilities and behaviour that challenges

	First choice (N, %)		*Second choice (N, %)*	
	Vignette 5	**Vignette 6**	**Vignette 5**	**Vignette 6**
Secure unit	5 (9.5%)	9 (18%)	10 (21%)	6 (13.3%)
Psychiatric hospital	5 (9.5%)	11 (23%)	7 (15%)	8 (18%)
52-week residential placement	18 (34%)	12 (25%)	9 (19%)	10 (22%)
38-week residential placement	0 (0%)	0 (0%)	3 (6%)	0 (0%)
Sub-total: residential-based settings	**28 (53%)**	**32 (66%)**	**29 (61%)**	**24 (53.3%)**
Living in supported accommodation	9 (17%)	4 (8%)	7 (15%)	6 (13.3%)
Living at home with community-based social and mental health care and positive behaviour support	7 (13%)	5 (10%)	4 (9%)	7 (16%)
Living at home with community-based social and mental health care (AMHS/CLDT)	6 (11%)	7 (14%)	4 (9%)	6 (13.3%)
Living at home with community-based social care	1 (2%)	0 (0%)	2 (4%)	1 (2%)
Living at home without any support	2 (4%)	1 (2%)	1 (2%)	1 (2%)
Sub-total: community-based settings	**25 (47%)**	**17 (34%)**	**18 (39%)**	**21 (46.6%)**
Total	53 (100%)	49 (100%)	47 (100%)	45 (100%)

Note: AMHS = Adult Mental Health Service. CLDT = Community Learning Disability Team.

Table 5 Care package costs for children with learning disabilities and behaviour that challenges

	Weekly cost (£, 2012-13)	**Annual cost (£, 2012-13)**	**Source**
Secure unit	£9,373	£487,396	Curtis (2013)
Psychiatric hospital	£4,529	£235,508	Curtis (2013)
52-week residential school placement	£3,292	£171,176	Clifford & Thobald (2012)
38-week residential school placement	£2,117	£110,108	Clifford & Thobald (2012)
Living at home with community-based social and mental health care and positive behaviour support	£1,642	£85,408	Iemmi *et al.* (2016a); Iemmi *et al.* (2016b)
Living at home with community-based social and mental health care (CAMHS/CLDT)	£151	£7,876	Beresford *et al.* (2012)
Living at home with community-based social care	£147	£7,652	Beresford *et al.* (2012)
Living at home without any support	£85	£4,445	Beresford *et al.* (2012)

Note: CAMHS = Child and Adolescent Mental Health Service. CLDT = Community Learning Disability Team.

Table 6 Care package costs for adults with learning disabilities and behaviour that challenges

	Weekly cost (£, 2012-13)	**Annual cost (£, 2012-13)**	**Source**
Secure unit	£3,696	£192,192	Curtis (2013)
Psychiatric hospital	£1,832	£95,263	Tyrer *et al.* (2009)*
52-week residential placement	£1,600	£83,212	Tyrer *et al.* (2009)*
38-week residential placement	£1,213	£63,101	Tyrer *et al.* (2009)*
Living in supported accommodation	£1,046	£54,398	Tyrer *et al.* (2009)*
Living at home with community-based social and mental health care and positive behaviour support	£2,296	£119,408	Iemmi *et al.* (2015)
Living at home with community-based social and mental health care (AMHS/CLDT)	£164	£8,514	Tyrer *et al.* (2009)*
Living at home with community-based social care	£151	£7,849	Tyrer *et al.* (2009)*
Living at home without any support	£9	£451	Tyrer *et al.* (2009)*

Note: AMHS = Adult Mental Health Service. CLDT = Community Learning Disability Team.
*Supplementary analysis of the NACHBID dataset.

Table 7 Weighted average weekly and annual care package cost for each vignette

		First choice		*Second choice*	
		Weighted weekly cost (£, 2012-13)	**Weighted annual cost (£, 2012-13)**	**Weighted weekly cost (£, 2012-13)**	**Weighted annual cost (£, 2012-13)**
Children	Vignette 1	£1,336	£69,447	£1,668	£86,759
	Vignette 2	£762	£39,612	£1,252	£66,078
	Vignette 3	£988	£51,374	£1,080	£56,179
	Vignette 4	£1,440	£74,876	£2,133	£110,923
Young people	Vignette 1	£815	£42,388	£1,105	£57,463
	Vignette 2	£678	£35,235	£985	£51,220
	Vignette 3	£897	£46,656	£990	£51,488
	Vignette 4	£1,016	£52,832	£1,186	£61,694
Adult	Vignette 5	£1,567	£81,478	£1,812	£94,239
	Vignette 6	£1,823	£94,799	£1,705	£88,651